"Picking Up the Pieces of Our Own Mistakes:" Supporting People with Co-Occurring Conditions

Charles Moseley Ed.D.
National Association of State Directors of Developmental Disabilities Services
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This paper reports on interviews conducted of five professional consultants who are actively working with state agencies, local providers, people with disabilities and their families, and direct care staff to respond to the needs of individuals with DD who have mental illness. The purpose of the interviews was threefold: (a) to document the perspectives of individuals with expertise in this area on the current state of services, (b) to identify the characteristics of effective programs and supports and, (c) broaden understanding of the barriers to effective service delivery. Interviews were open-ended, generally short, approximately 45 minutes in length, and focused on the practical issues individuals and organizations face in the support of individuals with co-occurring developmental disabilities and mental illness. The interviewees included John O'Brien, Michael Smull, David Pitonyak, Matt McCue, and Chris Heimerl.

The interviews were loosely structured around the three topical areas identified above. Discussions were free flowing, ranging across the interests and experiences of the respondents. Although each person brought a different perspective to the issues under consideration, four themes ran though their comments including: (a) relationships between developmental disabilities and mental health services, (b) the impact of standard service paradigms on the supports provided, (c) the role of staff and (d) the characteristics of successful programs. This paper summarizes the perspectives of the interviewees in each of these areas.

Background

The prevalence of mental illness among persons with mental retardation and other developmental disabilities is reported to vary widely depending on age, type of mental illness, and other demographic, social, and psychological factors. Mental illness prevalence rates among individuals with mental retardation have been reported to range from 20% to 35% (Stark, 1989) or, as noted in the DSM-IV[1], at a rate three to four times that of the general population. Surveys of individuals enrolled in community

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[1] Diagnostic & Statistical Manual of Mental Disorders (4th ed.) American Psychiatric Association, 1994.

MR/DD programs have reported incidence rates ranging between 10 percent and 40 percent, while large population studies have found somewhat lower rates (10% to 20% of the surveyed population) (Reiss, Goldberg & Ryan, 1993). Regardless of the statistical estimates, however, it is generally accepted that because of the nature of their conditions, individuals with developmental disabilities may be more apt to encounter the personal, emotional and social stressors that are associated with mental illness than are members of the general population (Bregman & Harris, 1995). While individuals with developmental disabilities may be at greater risk for developing mental illness, Numerous studies have documented how a diagnosis of mental retardation or developmental disabilities overshadows clinical treatment, particularly regarding access to mental health services (Reiss, Levitan & Szyszko, 1982; Sovner, 1986). Regardless of the difficulties associated with diagnosis, however, is appears clear that individuals with these co-occurring conditions are among the most challenging served by both the developmental disability and mental health service delivery systems (Jacobson & Mulick, 2002). Indeed, the ability to support people with developmental disabilities who demonstrate substantial behavioral disorders is widely perceived to be a critical measure of a local service system's capacity to act as a holistic alternative to institutional care.[2]

People with developmental disabilities who have additional, co-occurring diagnoses of mental illness, or who demonstrate severe challenging behavior present number of challenges to state funded systems of long-term care. In fairness, state funded systems of long term care present a number of challenges to people with co-occurring conditions. The fact is that in many states, existing systems of service delivery are just not up to the task. The problem is not necessarily a lack of support. Although services in some areas of the country have suffered recently due to declining state revenues, each state continues to fund comprehensive systems offering a range of supports to eligible individuals. Rather, the barriers to service delivery appear to stem from a number of interacting factors related to differences in treatment approach, funding authority, eligibility criteria, and professional expertise that combine to place the needs of individuals with co-occurring diagnoses just outside the scope of the services offered by each department. People with both developmental and mental health diagnoses literally get stuck in the service cracks between the two systems and, as a result, get a little of each.

The professionals interviewed for this report describe three key factors that play a major role in the provision of supports to individuals with developmental disabilities who

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[2] Gettings, unpublished manuscript

experience mental illness or demonstrate severe behaviors: (a) the challenge of integrating services between two separate systems of support and approaches to treatment, (b) the influence of the structure and functioning of the current developmental disabilities services system on the provision supports to people with co-occurring conditions and, (c) the role of staffing and program management. In addition, there was broad agreement among the individuals who were interviewed on the characteristics of services and programs that successfully met the needs of these individuals.

Integrating Developmental Disability and Mental Health Services: Relationships Between Departments

Individuals with developmental disabilities and people with severe and persistent mental illnesses are typically supported through different state agencies. Although both systems are designed to meet the needs of people with mental impairments, their respective program structures, policies, and methods of service delivery are quite different. Each system, for example, is anchored by statutory frameworks that are specific to the needs of the particular population served. As a result, developmental disabilities and mental health systems operate in accordance with separate regulations, employ differing eligibility criteria, and furnish supports through separate provider networks. Staff require different types of training and background and services are funded through separate appropriations.

Developmental disabilities systems are designed to provide long-term support to a relatively stable, albeit increasing, population of individuals living primarily in dispersed community settings. Services to individuals with mental health needs, by contrast, typically focus on the provision of short-term, outpatient psychiatric treatment, crisis intervention, counseling, stabilization and recovery. Comparatively fewer people receive long-term mental health care through psychiatric hospitals or residential programs. Although in a given state, the two systems may support the same numbers of individuals at any single point in time, during the course of the year the mental health program can be expected to come in contact with several times the number of individuals receiving developmental disabilities services during the same period.

The individuals interviewed during this study identified the structural differences between the developmental disabilities and mental health programs as having a significant impact on quality, continuity, and effectiveness of the services provided to individuals with co-occurring conditions. Although recognizing that such differences offer opportunities as well as service barriers, there was general agreement that in most

states the fit was not conducive to the development and implementation of stable systems of care for individuals with dual diagnoses. Matt McCue and Chris Heimerl noted that their state's mental health system is good at responding to acute mental health crises but frequently drops the ball on long tem support. The DD system, in contrast, has a better understanding of individuals' long term support needs, but falls apart when asked to provide emergency mental health services. They mentioned that providers frequently seem to be caught in the middle between the two programs, often being forced at the local level to resolve issues related to state policy regarding the long-term and intermittent services provided by both departments but not having the authority to change the underlying problem. Without access to adequate funding or technical assistance to deal with emerging problems, providers may have little capacity to respond to the needs of people in crisis. "Many times," they add, "providers talk of the need of challenging people for hospitalization to cure their mental illnesses, when what they are actually looking for is respite for overworked or under-trained staff."

David Pitonyak underscored the gap between developmental disabilities and mental health services, noting that mental health professionals typically have very little interaction with people with developmental disabilities or with DD service providers, and have neither the opportunity nor the need to figure out the treatment approach that works the best for this group of individuals. The problem is further complicated because the "group" of people with co-occurring conditions is by no means homogeneous. Each individual has different capabilities, different methods of communication and different life circumstances that significantly influence the nature of the treatment that is provided. Pitonyak observed that within each state there is a need for collaboration and honest talk about the nature of the support that the mental health system can and cannot provide to individuals with developmental disabilities. To effectively address the needs of this group, state developmental disabilities and mental health agencies need to collaborate on developing a plan for addressing the immediate problems that individuals and staff confront on a daily basic and institute some tangible activities to change the way services have been provided. People need to move beyond the current reliance on ineffective "SWAT" teams which give the illusion that people's needs are being met, but which in actuality are incapable of bringing lasting change to either people's lives or the system in general.

John O'Brien observed that in most states, both DD and MH professionals find it difficult to fully understand and grasp each other's perspective. He mentioned further that it seems particularly hard for mental health professionals to understand and recognize the long-term needs of people with developmental disabilities for support and assistance, and to accommodate their needs within the context of the community mental health system. He questioned the practicality of forcing the two systems

together when the difference may be too great. O'Brien put it this way, "It is a very real possibility that mental health is not able to provide the services that are needed; that the current design of mental health service delivery does not work for people with developmental disabilities and cannot be made to work to produce the outcomes required."

O'Brien explained that differences in the approaches utilized by each state agency may actively inhibit their ability to work effectively together. For example, mental health programs are designed to provide short-term treatment to

Mental Health	Developmental Disabilities
Episodic treatment	Long-term support
Medication and treatment	Individualized Diag/treatment
Communication	Difficulty w/communication
Cognition	Difficulty w/ cognition
Generic expertise	Specific expertise
Staff assistance not needed	Staff intermediary needed

individuals that may enter and leave the system frequently during the course of their lifetimes. Developmental disabilities programs, by contrast, are comprehensive, designed with the capacity to support individuals with intensive services throughout their lives (see chart below). Community mental health services frequently rely upon medication as a primary component of treatment, while developmental disabilities services typically employ individualized approaches and treatment interventions that are tailored to each individual's communication abilities and support needs. Further, individuals with mental illness from the general population are assumed to be able to communicate with the therapist and to improve their functioning by developing a greater awareness of their issues, while persons with developmental disabilities, are more apt to have difficulties with cognition and understanding. Mental health professionals are usually trained as generalists, with skills to address the varying needs of a wide range of individuals, while the treatment of persons with dual diagnoses require professionals with very specific expertise, training and experience. Finally, in contrast to individuals from the general population, those with developmental disabilities often require the assistance of another person to act as an intermediary with the psychiatrist or therapist to facilitate communication and understanding ensure all the necessary information is communicated. O'Brien noted that as a result of these differences it is not surprising that community mental health programs are not able to mount an effective response to the calls of developmental disabilities for assistance.

State agencies address the needs of individuals with co-occurring conditions in different ways depending on the nature of the DD and MH service systems, the personalities of the state and local officials involved, and the availability of professional expertise. Matt Mc Cue and Chris Heimerl described the efforts of the New Mexico state developmental disabilities agency to support individuals with dual diagnoses by

establishing a special needs clinic to provide mental health services. Staffed with trained psychiatrists who understand the need for consistent structure, strong and effective relationships, and who know how to apply psychotropic medication to help people with their problems, the program has successfully supported individuals in settings across the state. However, they observed, even with the clinic, the community developmental disabilities system continues to struggle with local mental health practitioners, physicians and psychiatrists who are not familiar with the needs of people with cognitive disabilities: "although some psychiatrists are good, others still believe people with DD cannot have a mental illness."

But, is collaboration unattainable, must the two systems be condemned to go their separate ways? Not necessarily, according to Michael Smull. Smull stressed the importance of state officials understanding where the strengths of each system lay and of the need to capitalize on the approaches that mental health and developmental disabilities programs have each determined work well with the individuals they support. He pointed to Post Traumatic Stress Disorder (PTSD), as an example of a condition that is increasingly being identified as a relatively common disorder among people with developmental disabilities. Treatment approaches exist that work well with members of the general population who have PTSD and for the most part the mental health system is able to adequately address people's needs. Yet, in many situations professionals have not been able to adapt approaches found to be successful in the field of mental health for application with people who have developmental disabilities. He noted that the ability or inability to successfully bridge the gap between fields has prompted some developmental disabilities state agencies to develop very strong collaborative relationships with their counterparts in mental health, and others to "go it alone" by creating the capacity to serve individuals with dual diagnoses without mental health involvement.

The respondents expressed considerable concern over the ability to the DD and MH systems to work together to address the needs of individuals with co-occurring conditions. There was general agreement that in the states where the capacity to meet the needs of individuals with dual diagnoses exists or is actively being developed; Vermont, Pennsylvania, Washington and Ohio, for example, very productive relationships appeared to exist among the staff and the leadership of the respective state departments - as well as with the medical community, particularly local psychiatrists. The importance of having effective clinical teams in place that are able to provide people with the supports they need to negotiate both the DD and MH systems was additionally recognized as a key factor. Michael Smull observed that the effectiveness of a program was strongly influenced by the personalities and working relationships of the individuals involved. When relationships are strained, no steps are typically taken

to bring the two systems, DD and MH, together to mutually address the issues presented by individuals with co-occurring conditions. On the other hand, when the relationships are positive, the two systems are able to collaborate to effectively address and resolve mutual issues.

While the presence of positive relationships between the two systems appears to be a necessary ingredient to successful collaboration, it was also noted that a system can become too dependent on the personalities of the leaders or people with expertise and might suffer when key issues that would otherwise stand in the way of service provision are not addressed and resolved. In general, the respondents agreed that there was no single "correct" or "fool-proof" approach to meeting the needs of individuals with dual diagnoses or particular "model" that a state could follow to achieve success. Differences in state regulations, departmental strengths and weaknesses, local conditions, staff availability, professional resources and others highlight the need for each to choose a method of providing supports to individuals with co-occurring mental illness and developmental disabilities that draws upon the assets that are available locally. Vermont and Ohio, for example, are effectively addressing the needs of people with co-occurring conditions by employing two different methods, one addressing the needs of people with dual diagnoses within the context of developmental disabilities services and the other developing capacity through intensive collaboration between the departments of developmental disabilities and mental health.

Differences between the DD and MH systems in the availability and disposition of financial resources were identified by all of the individuals interviewed as presenting major barriers to the development and implementation of appropriate services to individuals with co-occurring mental retardation and mental illness. Funding for typical outpatient mental health services was seen as insufficient to meet the needs of most individuals with developmental disabilities. It was noted that because of the availability of funds under the DD home and community based waiver, most of the individuals with dual diagnoses end up receiving support through the DD service system.

"The Standard DD Service Paradigm Needs to Change"

It is important to see where referrals are coming from – the problem and the need may be iatrogenic in nature. It may come out of the nature of the services that are provided.
<div align="right">John O'Brien</div>

There was general agreement among the interview respondents that the existing state sponsored systems of service delivery were frequently inadequate to meet the needs of

people with co-occurring conditions. The barriers to support provision that exist in the design, funding and content of services can interact to create what is described by McCue and Heimerl as a "culture" of service provision that makes it acceptable for providers to refuse to support certain individuals. While it may appear inappropriate and perhaps even unethical for providers to deny support to eligible individuals, the refusal to serve is most likely the symptom and not the cause of the problem. The lack of appropriate policy to guide an effective response to the needs of individuals with co-occurring conditions, the presence of exclusive program requirements and the absence of flexible systems of financing in many states have resulted in system designs that effectively inhibit service delivery.

The Impact of Current System Design on Service Delivery

Each of the respondents discussed the impact a system's structure has on the people receiving support and how a program's design can facilitate service provision or block the best efforts of both caring staff and professionals to achieve positive change. Key structural factors influencing both the quality and effectiveness of the services include: (a) the existing "upstream" structure of the DD and MH systems; (b) the design of the services that are offered, and; (c) the level of control provided by the system itself.

John O'Brien observed that it is important for policymakers to identify and acknowledge the barriers that influence support delivery and to pay particular attention to the impact of the "upstream" services that are provided to individuals with dual diagnoses on the demand for assistance, the frequency of crises and the nature of the programs that need to be provided. States with highly individualized services, for example, have the flexibility to adjust to meet an individual's changing needs for support and assistance, and as a result can be expected to provide many specialized mental health supports within the context of the current system. States with more traditional system designs, in contrast, may be less able to tailor a response to individual situations and may require external interventions that provide more structured and formal programs of support.

The respondents expressed both frustration and impatience with current service designs noting that both developmental disabilities and the mental health systems must change if the needs of individuals with co-occurring conditions are to be effectively addressed. Heimerl and McCue put it this way, "For people with dual diagnoses, or who commit acts of serious aggression against others, the paradigm needs to shift to one emphasizing the humanistic application of external structure." They stress the need for individualized services within single rather than group placements where both the environment and social interactions can be controlled. In this atmosphere, both the staff

and the person receiving support can more effectively develop confidence in themselves and in their mutual relationship; confidence that can lead to the development of a sense of security and respect. External control can have a significant influence if it is designed to enable a person to access a life. But this type of careful, humanistic control is not easy to access or to build into programs. O'Brien notes that there is a very real possibility that current design of the mental health system is not able to accommodate to the needs of individuals with developmental disabilities and is not able to produce the outcomes that are necessary for successful community living. David Pitonyak stresses the importance of blending external control with a focus on the development of the personal skills, confidence and self-respect that are necessary to sustain enduring behavioral change. People with developmental disabilities who experience mental illness need to be able to form long-term positive relationships with others in settings that are stable, predictable and provide a reliable level of safety and security.

The Content of Services

While the structure of the program or approach that is used is important, it cannot easily be separated from the content of the services that are provided – nor is it appropriate to make such a separation. Smull noted, for example, that looking at the population in general there are relatively few individuals who are truly clinically challenging. Many in the system are "just screwing up" in response to the chaos in their lives caused by inconsistent services, staff turnover, or inappropriate support paradigms. Unfortunately, when staff are confronted with people who do not respond positively to what the system has to offer, the all too frequent response is to intensify the particular intervention that is not working. Increasing the service dosage, in the absence of a careful analysis of the circumstances under which the particular "inappropriate" behavior is occurring rarely is effective. The individual's response may, in fact, be a totally appropriate reaction to an inappropriate set of circumstances or particular situation.

Smull emphasized the importance of effective service planning, noting that when staff, professionals, people with disabilities and families work together to develop a person-centered or "essential lifestyle" plan, they develop a common way of thinking and a common language. "People need to focus on what is important to individuals receiving support and then consider what is important for those people." He notes further that generally the system does a marginal job determining what is important for people, but a really "lousy" job determining what is important to people.

The need to focus on the individual receiving support was echoed by the other respondents who commented on the changes that have taken place as developmental disabilities professionals expand their understanding of the nature and impact of mental illness on the people they support. As psychiatry moves away from outdated notions that people with mental retardation and developmental disabilities are incapable of having mental illness, professionals are increasingly becoming aware of the impact of past experiences on current behavior. Post Traumatic Stress Disorder, for example, was repeatedly referenced as a condition that has only recently been identified as having a significant impact on the lives of many people with developmental disabilities. It was also noted that new and innovative approaches are being developed in several states across the country.

While advances in treatment methodologies are being achieved through increasing awareness of the needs of individuals with dual diagnoses for appropriate services, much less clarity seems to exist on the nature of the services that should be provided. A survey of state DD and MH directors conducted in the spring of 2003 by the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the National Association of State Mental Health Program Directors (NASMHPD), revealed that key barriers to service provision included inadequate information on best practice (reported by 67% of the respondents) and the shortage of qualified providers (reported by 78% of the survey respondents).

Although the interview discussions primarily focused on systems issues, the respondents did identify some of the key characteristics of the clinical services that appear to effectively address the needs of individuals with dual diagnoses. The importance of the interaction between the structure of the program and the nature of the supports that could be provided was highlighted by comments from Matt McCue and Chris Heimerl. McCue and Heimerl emphasized the importance of having reliable staff who had the ability to provide individuals with consistent expectations, clear limits, and positive support over time. Sometimes, they observed, the need for a support atmosphere that is less permissive than that of typical DD programs and more reliant upon external control is hard for staff to reconcile. Staff need to understand that for some individuals the least restrictive environment may be one that limits access to community activities or particular individuals. They put it this way, "staff need to be able to determine when choice no longer applies. Without the structure, people receiving support do not know who to trust. Uncertainty confirms their fears that the world is chaotic and unpredictable." Developmental disabilities services over the years have moved away from the highly structured approaches that some people need to organize their lives. The challenge is to integrate structure within an overall construct that continues to support the "dignity of risk" and increasing levels of responsibility

through successive explorations of life. Focus shifts to attempt build feelings of personal autonomy by developing and strengthening the skills of self management and internal control.

Getting There from Here: The Role of Staff

For services to be successful, people with challenging behaviors need to be able to trust those who work with them, to believe that people will stick with them through thick and thin. David Pitonyak, referencing the comments of Al Vecchione, an innovative service provider in Vermont, noted that "we need to lavishly invest in the staff hired to support these folks." Pitonyak noted that the quality of the attention that individuals with challenging behaviors and co-occurring conditions need is difficult to achieve within the context of programs that experience high rates of turnover and have limited resources available to invest in staff development and support. People receiving support are traumatized by staff turnover yet are placed in situations where they need to form new relationships with an ongoing series of unfamiliar staff. He observed that the current publicly funded system frequently has little ability to sustain appropriate and positive treatment approaches to people with co-occurring conditions over time. Effective and appropriate living situations deteriorate and the system loses the ability to identify the point at which a situation begins to fall apart and to take the actions necessary to place things back onto a firm footing. "The system," Pitonyak notes, "is picking up the pieces of its own mistakes." Interventions that are made do not reflect an understanding or awareness of the successes and failures of the past. Professionals do not consider the circumstances that were in place the last time the individual was doing well; the last time he or she was happy, and achieving some degree of success. They do not take into account how the personal or living environment has changed, relationships that have fallen apart or new ones that have been developed. "When people are not in the right relationships with others they become stressed. There is a greater likelihood that problems will occur, that things will fall apart because they are afraid or because they do not have confidence that they can return to a place of security." Services need to be designed to help an individual build a sense of confidence that he or she is capable of change, can achieve success and can have realistic hope for a better future.

All of the individuals interviewed stressed the importance of effective, knowledgeable, and consistent staff. It was noted that many times providers assign staff with the least experience and the fewest skills to work with people with the most intensive problems in the most challenging of situations. This "trial by fire" approach creates impossible situations for all concerned and generally leads to an increase in the very behaviors or conditions that need to decrease for a successful adjustment to occur. People with the

most challenging needs must be supported by the most skilled staff. Staff training should happen often, regularly and focus on the issues that are directly related to people's needs for support and assistance, attachment and positive relationships, fears, diet and depression. State agencies need to focus the development of strong and mutually valued match between individuals with disabilities and the staff hired to provide them with support and training. Positive relationships between staff and individual receiving support need to be backed up with good medical care and a holistic approach that enables the person to develop confidence in his or her ability to build a new life.

What Works: Characteristics of Successful Programs

The individuals contributing to this paper spoke of the complexity of the issues involved, the interrelationship of the many factors that must be brought together if services are to be effective, the costs of "appropriate" support, and the issues that confront both developmental disabilities and mental health systems. The challenge is to integrate the lessons that have been learned into an approach that can be used to guide the design of effective and appropriate practice standards.

What then are the characteristics of successful programs, and what are the steps state officials should take to develop and implement services to people with co-occurring conditions that have a positive impact on their lives, that change behaviors? Successful interventions appear to pay considerable attention to the following components of support provision:

1. <u>Emphasis on Relationships.</u> People with co-occurring conditions need to have the opportunity and the support necessary to form positive, long-term relationships with others. They need to live and daily interact with people who value them as individuals, who are committed to their well-being and who demonstrate confidence in the person's capacity to learn, change and grow.

2. <u>Relationships with Other Organizations and Groups</u>. Regardless of the structure of the state's program, the needs of people with co-occurring conditions frequently extend to other departments within state government, such as mental health, substance abuse, health, children's services, and to the medical community at large. Positive relationships with other groups or agencies facilitate training, support provision, and the general organization of service delivery.

3. <u>Individualizing Services.</u> Effective services utilize flexible program designs that can be tailored to the particular needs of each person receiving support. All of the professionals interviewed emphasized the need to respond to people with co-occurring conditions as individuals, supporting them in highly personalized settings that provided them with the space, security, support, and role models they need to learn new ways of interacting with the world.

4. <u>Develop Staff as a Resource</u>. Effective programs see the staff that provide individuals with support, assistance, guidance and treatment as a resource worthy of considerable investment, respect and involvement in decision-making. Staff are well trained and understand the importance of their role in the lives of those they support.

5. <u>Leadership.</u> All of the individuals interviewed stressed the importance of clear and unequivocal leadership that is innovative and willing to "do whatever it takes" to ensure the person receiving support has the tools and assistance he or she needs to succeed in life. Program managers hold individuals in high regard, they do not give up on the person, and they do not accept failure as an option.

6. <u>Flexible and Adequate Resources</u>. Regardless of the particular approach used, individuals with co-occurring conditions are among the most costly to support. To effectively address the complex needs of individuals with co-occurring conditions, programs need not only stable sources of funding to ensure the continuity of existing services, but also have access to separate resource allocations that are able to be used in highly flexible ways to provide immediate assistance as necessary.

7. <u>Zero Reject</u>. Successful programs demonstrate a commitment to supporting individuals in community settings regardless of the intensity of the person's needs.

Summary and Next Steps

This paper reports on interviews conducted with five professionals who have considerable expertise in the design and implementation of services and supports to individuals with co-occurring developmental disabilities and mental illness. Each person was asked to provide his perspective on the current status of programs and services supporting individuals with co-occurring conditions. Their comments ranged widely across the many variables that influence the design and operation of services to individuals with developmental disabilities who have diagnoses of mental illness or

who demonstrate challenging behaviors. Drawing from their experiences with individuals with disabilities, families, program administrators and clinical professionals the interviewees provided a great deal of information on the current *state of play* with respect to services provided to individuals with dual diagnoses. Throughout the course of the discussion, the consultants expressed a number of thoughts, opinions, observations and conclusions that can be offered as suggestions for the development of systems of support delivery that are responsive to the needs of individuals with co-occurring conditions.

The information summarized in this document will be used to inform the development of a survey of state directors of developmental disabilities services on the nature and extent of services and supports provided to individuals with co-occurring developmental disabilities and mental illness in their respective states.

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For Further Information contact:

Charles Moseley Ed.D.
Director of Special Projects
National Association of State Directors of Developmental Disabilities Services Inc.
TEL: (703) 683-4202
Email: cmoseley@nasddds.org